

# MD NEWSLETTER

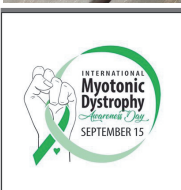
of Myotonic Dystrophy Support Group

This get together was organised by our Patron, Professor David Brook.

He made a very appetising sponge cake (he is a good cook). He invited Mike Walker and Margaret Bowler to join the celebration for all of the birthdays during the last year. In the photo, Prof David Brook with members of the Research Team from David Brook's Laboratory, Nottingham University.



We met on a windy day, it took several attempts to light the candle. David said everyone was 'Number One'.



## MYOTONIC DYSTROPHY INTERNATIONAL AWARENESS DAY

### 15 SEPTEMBER 2021

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2021**

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**MD**

Myotonic Dystrophy  
SUPPORT GROUP

## National Co-ordinator

Margaret Bowler

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M Bowler  
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P Ferrari  
C McAlonan  
E Ormandy  
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## Hello to all members of MDSG

I will make you smile - On the way home from the office I passed the petrol station and saw the display 13 19 in large letters. I said out loud to myself "I didn't think it was that late!" I was reading the price of petrol as a digital clock 13 19!! Another smile, When hanging the washing out I picked up the pegs from the soil, Who decided to grow pegs in my garden!

I do trust that you have had a little freedom from the lockdown, people with Myotonic Dystrophy are vulnerable, and you will have been "indoors" for so long it must have seemed for ever! I haven't been on a bus or train for over a year. I hope we can eventually plan for 2022, but not yet. Please do give a thought to suggesting a medical topic that you would like one of the invited doctors to talk about, so that we can have a better and clearer understanding of the subject. If you have any ideas about the conference do please email, write or phone us, as the conference is for us all to learn more. Prof Benedikt Schoser kindly sent his text of the presentation he had prepared for one "possible" 2021 conference. We have used this text to make a booklet.

Today Julie our MDSG office secretary who has been furloughed for months is back at her office desk. During her time away Mike Walker has been typing letters and other office duties while continuing to oversee MDSG finances. I will give him a gold star!

Enjoy reading this newsletter. Keep safe, have the Jab. Greetings from  
**Margaret Bowler**

## Letter from The Editor

Hello to all readers.  
Welcome to our Newsletter with articles that include news and views, suggestions and updates. Thank you as always to all our contributors. Wherever you are, we do hope that you keep safe and well in spite of the ongoing Covid 19 discussions and, for some, our July weather extremes to cope with.

Like most people with family members who have Myotonic Dystrophy, I had my vaccine jabs earlier in the year, both for my own protection and for theirs. Last week I was required to take the Covid Test (LFT) in order to access the Neuromuscular Centre, Winsford with my daughter, Lynne. She ordered the test online, (these can also be obtained from local chemists), which came as a pack of 7 individual tests via Royal Mail the next day. The complete pack leaves nothing to chance, even tells you that you will need tissues to hand. We familiarised ourselves with the various components, cleaned a flat surface, washed our hands and... well at this point I really didn't want to think too much about the next steps. Did I really want to stroke each tonsil with a swab and then put the swab up my nostril and give it a twirl? **BUT I DID!!** Phew. It's not a pleasant test to do either to self or to another person, but very necessary at times. Afterwards, sneezes seem to be obligatory.

If your fingers are affected by Myotonic Dystrophy, do enlist the help of someone else just in case you can't twist a top, squeeze a tiny plastic container, direct the dropper etc. We found the recommended YouTube video helpful as a good introduction to the test. Good luck. Keep safe and well.  
With warm wishes,

**Elycia Ormandy**



## Myotonic Dystrophy International Awareness Day 15th September 2021

I am asking if all our members would try and talk to someone about Myotonic Dystrophy on 15th September 2021. It could be a relative, a neighbour, a GP or a school teacher anyone you come in contact with. We can all be involved with the Myotonic Dystrophy International Awareness Day. Several countries are taking part.

### Contact People

We are sorry to have received the news that two of our loyal Contact People have had to step down from this role. We want to take this opportunity to thank both **Ann Cobburn** (Glasgow) and **Rachel Reeson** (Sheffield) for all that they have offered to the MDSG members and others by offering time energy and commitment since taking on this worthwhile role.

Contact People/Families are all key people in the day to day life of MDSG. They volunteer listening, signposting, fundraising efforts, organising meetings, contacting, planning etc.....In addition Ann has taken responsibility for overseeing, regularly emptying and forwarding the money from the MDSG collecting boxes from her area. She tells Margaret that she hopes to continue her Fundraising. So, we send you our sincere thanks for all you have offered to the MDSG. Your contribution HAS made a difference. We will miss you both. Keep in touch.

### Acknowledgements

Thank you to all those members who have renewed their membership, those who have sent in donations. Thank you also to those who have lost loved ones and asked for donations to be given to MDSG. A number of people have remembered MDSG in their wills and left legacies by way of money or in some cases even property.

*Wherever possible, we like to acknowledge your gift in whatever form it comes. Unfortunately, we do not always have the information.*

Please accept our apologies if you have not had an acknowledgement for past donations. If you make a payment through the bank or via our website please state what the donation is for, whether it be in memory or a gift in lieu of a special birthday or maybe your membership subscription. If you have made a donation along with your subs, via these methods, unless you tell us we will not know you have re-joined and we will assume you are not a member and you will not receive the benefits such as a newsletter.

**If you think we have missed you, please contact the office and let us know.**

### Fundraising

Despite the pandemic, a number of people have been or are doing fundraising events for MDSG.

**Bradley Collett is doing a bike ride from Central London to Amsterdam on 3 September 2021.**

It is a two day event and he is doing it in memory of his friend Alex Thurston who had myotonic dystrophy and passed away in 2018. This bike ride event will be dedicated to Alex and to spread awareness for those who are unaware of Myotonic Dystrophy.  
<http://www.justgiving.com/this-one-is-for-alex>

**AND**

**Richard Washington and his cousin James are doing the Bournemouth Half Marathon on 10 October 2021.**

Richard is doing it in memory of his big sister Tina Washington who had myotonic dystrophy and passed away in 2017. Tina sailed in the BT Global Challenge yacht race on the BG Spirit boat in 2004/5. She crewed on the Cape Town to Boston leg and they won it (and won the overall world race for good measure). He writes; "if Tina could sail from one continent to another and win the race, then I think we should be able to run along a beach for 2 hours!"  
<http://www.justgiving.com/runwithjamesandrich>

### Vaccine

I have myotonic dystrophy and have received two Astra Zeneca vaccines. The first on 14 February and the second on 24 April. I have had no major side effects except for a slight ache in my arm. I feel safer for myself and other people having had the jabs.  
Thank you, **Heidi Taylor (Darlington)**

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### Three Peaks Challenge 5 June 2021

Daniel Barber has just completed the Yorkshire Three Peaks Challenge, he is son of Pauline Ferrari, wife of MDSG trustee Peter Ferrari.

Daniel writes, "My dad, John Barber, was diagnosed with Myotonic Dystrophy in 2012 and passed away in May 2020 after contracting Covid-19. After a really difficult year due to dad's passing and the pandemic, I felt the time was right, with lockdown restrictions easing to do something in memory of dad and to try and raise some funds for MDSG, who were a huge help to dad and the family.

So early on Saturday, 5th June, me and a group of four friends, Andrew, Mat, Matt and Steve set off from Wakefield on our quest to complete the Yorkshire Three Peaks Challenge. Starting and finishing in Horton-in Ribblesdale, the walk involves climbing Pen-y-ghent (691m), Whernside (728m) and Ingleborough (723m) in under 12 hours. A total of just under 25 miles. Sore and exhausted and on what was probably one of the hottest days of the year, we managed to complete the walk in a respectable 10 hours and 5 minutes. Another friend also called Matt (I know a lot of people called Matt!), who was unable to start with us at 7am, finished an hour or so after us in a bonkers time of 6 hours 20 minutes.

I'd like to thank my five friends who supported me on this challenge and helped me raise just over £1,000 for the MDSG. I have been totally blown away by everyone's support and generosity; I set my target as £100 and never envisaged being able to raise such a significant amount. I'm sure dad would have been extremely proud and the MDSG will put the money to good use supporting other people with MD and their families." **Dan Barber**



### University of Glasgow

Dear Mr Walker & Myotonic Dystrophy Support Group,  
I am writing to thank you for the recent donation of £350 towards Myotonic Dystrophy Research, and to extend special thanks for your continued support to the University. As the generosity of our donors and friends continues to grow, it is inspiring to see how the impact of philanthropy is felt by staff and students across Glasgow.

*Professor Darren Monckton's lab are developing new approaches to population level screening of the mutations that cause myotonic dystrophy types 1 and 2. This will allow them to define the true incidence of the condition, understand the origin of new families with the condition and facilitate the identification and treatment of families before the onset of non-reversible symptoms. Most excitingly, this data is providing unique insights into the molecular basis of the symptoms and suggesting novel new ways of treating the disease*

Thank you again for your support. If you have any questions about your gift or would like further information about our work here at Glasgow please do get in touch via my details below.

Yours sincerely,

**Danielle McLaughlin, Supporter Engagement Officer, University of Glasgow**

## Covid Follow Up Dr Chris Turner

It is often difficult to know when major events start and finish in life but for the second Covid surge in December 2020, the start was very clear.

There had been a few concerning phone calls in mid-December and snippets of data which raised eye brows, but the spirit of a much needed Festive break for staff was in the air.

There may have been a touch of disbelief, on reflection, that a true Covid surge could be so cruel as to tear this one event away from so many teams who were looking forward to their short lived escape. Teams that had already spent the past 9 months coping with unparalleled circumstances.

Turkeys and puddings and presents and 'social bubble' relatives all needed transporting and welcoming.

On the Monday morning of 21st December 2020, our Covid landscape changed with a ferocity that no one fully predicted.

For many staff, their much-deserved Festive break was so close and yet would have to wait for another year, cut short in a moment of realisation that the inevitable was happening.

The Covid surge in March could be compared to a climb up Ben Nevis-a steady but uncertain path with turnings one could not predict over a day or two.

The December Covid surge was similar to climbing Mount Kilimanjaro-a long and arduous hike over several days that required grit, determination and stamina with predictable fallout from the relentless size of the task.

I have personally had to ask (or plea) so many staff, to do so many things, with so little notice.

It would be wrong of me to highlight one story to you, as it would not do justice to those not included. However, when doctors become health care assistants and fill shelves with endless flows of life-supporting consumables, when nurses care for many times more lives than is familiar, when therapists provide news for separated families who hang onto every word of hope for the lives of loved ones, and managers, who have never stepped into the frenzy of a busy Intensive Care become part of a life-saving "proning" team, then, and only then, do you realise the enormity and power of the human spirit to climb unsurmountable peaks in our heads and in our hearts.

We all owe a debt of gratitude to those who played their role. You have touched the lives of many and this is your enduring reward.

Our hope now lies in the vaccines and that soon we will look back on the mountain that was climbed with a sense of self-worth that "We all

made a difference". Staying at home makes a difference. Supporting your elderly relative in their home makes a difference. Seemingly endless home schooling makes a difference.



Queen Square needs to be proud of the role it played in the wider sector in taking Covid and neuroscience patients from a broad geographical area to support local ITU responses to Covid. Many of our ITU patients did not start their patient journey local to UCLH.

The future still has an air of financial, professional and personal uncertainty and we are supporting all the teams to return to pre-covid activities as part of our recovery plans. As a Trust, we would like to maintain many of the positive developments that came out of our Covid response, including virtual access to clinics, as well as continuing to develop our acute neuroscience services at Queen Square. The Covid pandemic has also brought into sharper focus, the physical and mental wellbeing of our staff. The quality of our clinical services is dependent on our teams being engaged, healthy and motivated.

Many thanks to all the staff at the MDSG who played their role in making a difference with their generous donations in supporting Myotonic Dystrophy. Your contribution brought many smiles to many people!

Now that the vaccination programme has gone so well in the UK, we can all hope that we can put as significant part of the pandemic behind us. We will need to be vigilant in looking out for new strains that the vaccines be less effective against but I enter the Summer with cautious optimism. There are currently many pharmaceutical companies who have an interest in developing treatments for DM.

Their programmes are at various stages from the earliest stages to phase 1 and 2a Trials. Please watch out for more information over the next year and I would strongly advise that you sign up to the National Myotonic Dystrophy Registry (<https://www.dm-registry.org.uk/>) so that you can keep abreast with the latest developments as well as receiving potential offers of joining clinical trials.

We also need to look forward to the development of a National Care Standards for DM which will enable a standardisation of clinical surveillance throughout the UK. All people with DM in the UK should have equal access to the most up to date services to support their journey with DM1.

Let us now go forward and look to a brighter future where the lessons of the past year can lead to greater awareness and translation of the needs of all people with DM.

**Dr Chris Turner**

**Dr Chris Turner is one of our advisors who works in Queen Square London**

**Dr Ian Bowler**  
is one  
of our  
advisors  
who  
works  
in the  
Cardiff  
Area

## **Painkillers and Myotonic Dystrophy – what is safe?**

This questions gets asked quite a lot – especially about painkillers after surgical operations, but the principles are the same whatever you take painkillers for. Here is some information on some of the commoner types of painkiller:

**Paracetamol** – Nearly everyone can take the normal dose of paracetamol with the normal spacing between doses – 1g (two 500mg tablets) four times a day. Be careful as paracetamol is often combined with other medication and you should not take more than the recommended maximum – 4g every 24hours – whether this is in combination or on its own.

**Non-Steroidal Anti-inflammatory Drugs (NSAIDs) – e.g. Ibuprofen, Naproxen, Diclofenac.** People with MyD are not more sensitive to these types of drug, though many people cannot tolerate them for long term use, as they cause stomach irritation, heartburn, and ulcers sometimes. They can also make asthma worse. You should not take them if you are on blood thinners like warfarin or apixaban. Check with your pharmacist to make sure that they will not interfere with any of your other tablets.

**Codeine / Dihydrocodeine –includes co-codamol / co-dydramol / Tylex etc -** this can be bought over the counter in small doses or by prescription only as stronger forms. All codeine-like drugs are converted to morphine in the body and therefore people with MyD may be sensitive to them. This DOES NOT mean you cannot take them. Everyone is different – regardless of whether they have MyD or not – so you have to be careful if you have not had them before. There are also lots of different strengths of codeine, either on its own or in mixtures with paracetamol. Take the smallest dose possible first (break a tablet in half) and give it twice the recommended time in-between doses.

If you don't get any severe side effects – drowsiness, nausea – then you can slowly increase the dose and frequency with which you take them.

**Tramadol** – this is a strong painkiller with some morphine-like properties. Do not take unless under the supervision of your doctor.

**Oxycodone – Shortec / Longtec.** These are also strong morphine-like drugs, usually given post-operatively. Make sure whoever prescribes them for you knows you could be sensitive to them and use the guidelines as for codeine.

**Oral morphine** – includes oromorph liquid, sevredol, MST, many other brand names. Make sure you know what dose you have been prescribed and again, start with the smallest dose possible and increase slowly.

When people have chronic pain conditions they are often prescribed drugs that are not primarily painkillers – usually for nerve pain. Drugs for epilepsy and antidepressants are often used for this. Make sure that whoever prescribes them for you knows that you could be sensitive to them and start with as small a dose as possible.

While it's important not to get too many side effects from painkillers, remember that being in pain is bad for you, as it stops you breathing deeply, sleeping, or moving around properly. It is very important to use the painkillers you do have as efficiently as possible. Use the weakest ones – usually just paracetamol – regularly as background pain relief and use the stronger ones in between. Don't forget other non-medicinal things are also good for pain – heat and cold, TENS, acupuncture and relaxation techniques can all help.

If you are unsure always ask someone first – your GP / Pharmacist / Hospital specialist will all be able to help.

**Dr Ian Bowler**

## Thank you Julie

Many members have telephoned the office and have spoken to Julie who is the Charity's secretary. Julie will have helped you with your enquiry.

In August, Julie retires. Julie has been the secretary of MDSG for 17 years. One of the things Julie regularly did was typing letters that I had written. How she managed to read my writing I will never know!

Julie would say 'I have done my best', meaning, "I have tried to read your writing!"

Recently Julie was furloughed, but is back in the office now and will continue with us until the end of August. Thank You Julie for all your filing, photocopying, phone answering and all the other things you have been doing over the years. We were a good team! **THANK YOU.**

**Happy retirement Julie**, from Margaret.



*Taken outside the MDSG office on a rare sunny day.*

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## Scribbler of the Year!

*Margaret has written about her exploits as a Community Midwife in Carlton/Gedling area of Nottingham. 60 pages of lots of stories, many funny situations throughout her career. Front cover shows Margaret by her first car.*

### Scribblings of a Community Midwife

1953 - 1998



Margaret A Bowler

*If you wish to buy a copy of her book at a cost of £10, please contact Margaret via the office. Funds from the sales are going to DEBRA towards research for Epidermolysis Bullosa.*

## Annual General Meeting and Conference

Following the latest Government advice, we are still unable to meet even in small groups. It is unlikely that we will be holding an Annual Conference this year, especially given the time it takes to organise and find a suitable venue at short notice.

We are nevertheless complying with the Charity Commissioners guidance and the accounts and Annual report which have been signed off by the Auditors CA Plus of Nottingham have been lodged with both Charity Commission and Companies House. This fulfils our legal obligation.

***If any member wishes to view the accounts for the year ending 31 December 2020, please contact the office.***

## Regional Group Contacts

The numbers below enable you to make contact with someone else in your region. Phone to ask about local meetings, provision of services in your area for families with neuromuscular conditions, or to discuss concerns. Is your area represented?

**Aberdeen**  
Jenny Watt  
01224 580559

**Cardiff**  
Margaret Ware  
02920 869277

**Croydon**  
Lesley Smith

**Cumbria**  
Neil Braiden  
01228 512385

**Devon**  
Josephine Holmes  
(contact office)

**Dorset and Hampshire**  
Ruth Harrison  
01425 626133

**Glasgow**  
Michael Kneafsey  
01360 311440

**Kent**  
Kirsty Blount and Amanda Scott  
01622 764824/01622 764347

**Kingston-upon-Thames**  
Penni Cotton  
(contact office)

**Manchester, North West and North Wales**  
Elycia Ormandy  
0161 445 5844

**Northampton / Milton Keynes**  
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07831 347143

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01740 620707

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Margaret Bowler  
0115 987 5869

**Sheffield**

**Somerset**  
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07748 636122

**South Birmingham and Worcestershire**  
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01527 64988

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01424 421013  
Rita Clarke  
(contact office)

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Pauline Ferrari  
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Jack Lawrence  
01977 790886



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**Patron:** Professor J. David Brook - Professor of Human Molecular Genetics, University of Nottingham.  
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